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ABSTRACT

This paper describes experiences in seeking and using after-school child care of 66 parents whose children (ages 5 through 16) have moderate to severe disabilities. Using the parents' own words, the paper shows how lack of child care has affected these people in their employment choices and personal lives. Data from 67 completed questionnaires are summarized in what is meant not as scientific sample but more as "a series of snapshots." Among findings were the following: that mental retardation was the most common special need; that older disabled children were substantially more likely to be refused admission to a child care program than younger children; that 40% of the sample's children were currently enrolled in after-school child care services; and that 61% of the parents preferred the mainstreamed child care environment. The strengths and weaknesses of mainstreaming in child care services are given special attention. (PB)

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"A QUIET FIGHT ALL THE WAY": A REPORT ON THE NEED FOR CHILD CARE AMONG PARENTS OF SCHOOL-AGE CHILDREN WITH HANDICAPPING CONDITIONS

Dale Borman Fink

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"A QUIET FIGHT ALL THE WAY"

A Report on the Need for Child Care Among Parents of School-Age Children with Handicapping Conditions

by Dale Borman Fink
Research Associate

The research reported here was funded by the A.L. Mailman Family Foundation of White Plains, New York. An additional grant from MONY Financial Services of New York, New York, supported the writing and dissemination of the findings.

This paper describes the experiences of parents whose children have mental, emotional, physical or other kinds of disabilities in seeking and using after-school child care. Drawing largely on their own words, it also reveals how the lack of child care has affected them in their careers and in other aspects of their lives.

Note: This paper is adapted from one chapter of a book scheduled for publication by The Exceptional Parent Press, Boston, in June 1988, to be titled *School-age Children With Special Needs: What Do They Do When School Is Out?*

"A QUIET FIGHT ALL THE WAY"

In response to growing numbers of questions from the field about the enrollment of children with special needs and handicapping conditions in child care programs, the School-Age Child Care Project undertook a study in the fall of 1986, with funding from the A.L. Mailman Family Foundation in White Plains, New York, and MONY Financial Services in New York, New York. Its purpose was to examine the growing supply of school-age child care programs across the United States to determine the extent to which children and adolescents with disabilities or handicapping conditions were being included in these programs, and to identify high quality models that did include this population and could be replicated.

One component of this School-Age/Special Needs Project was a study of parents whose children had moderate to severe disabilities and were between the ages of five and sixteen years of age. We wanted to know more about the extent to which parents of this population were using child care, felt a need for child care, or had made choices about employment based on the presence or absence of child care. It is the results of that study which we examine in this paper.

The study did not presume to create a scientific sample but rather to take what we called "a series of snapshots" that would convey the current state of reality for families of school-age children with special needs who were using child care, who had sought to use child care, or who simply had thoughts to share with us about the issue of child care in their lives and the lives of their children. We obtained our pool of respondents by sending news releases about our study to a wide variety of publications, including those read by the general public as well as those read primarily by families with disabled children. When parents wrote to us for information, we mailed them a brief, 10-question questionnaire.

The following information is gleaned from a total of 67 completed questionnaires; our 66 respondents (including one with two school-age sons with special needs) came from 22 different states. Smaller communities such as Syosset, New York; and Dracut, Massachusetts; and medium-sized cities, such as Oakland, California; Austin, Texas; and Montgomery, Alabama; were more represented in our sample than were rural areas and the nation's largest cities. On the whole, the respondents were thoughtful and articulate parents who offered much more than cursory responses to our questionnaire. In the following pages we describe the types of handicapping conditions faced by the families who responded to the survey and then examine their experiences with the issue of child care.

Ages and types of disabilities of children

The 67 responses were obtained in approximately equal numbers from parents of 5 year olds through 16 year olds. The children they reported on included 16 five to seven year olds, 24 eight to eleven year olds, and 27 twelve to sixteen year olds.

There was wide-ranging diversity in types of disabilities reported. Our stated purpose was to focus on children with moderate to severe disabilities. In keeping with that purpose, well over 90% of the children whose parents filled out the surveys appeared to fall in the moderate to severe range. For instance, there was only one child for whom "learning disabled" was the sole special need described. In the space on the questionnaire asking them to "briefly describe your child's disability or special needs," approximately half of the respondents named a single disability while half described two or more types of disabilities. Even some of those who listed only one were listing conditions, such as cerebral palsy, which often embrace more than one area of disability.

Various forms of mental retardation were the most commonly mentioned special needs. There were 36 children, or 54% of our survey sample, with identified mental disabilities. There were 22 children in our survey--33% of the sample--with identified physical disabilities. Sensory impairment and speech/communications disabilities, with 18 children, or 26% of the total, comprised together the next largest category represented in our survey sample. Behavioral and emotional disorders were identified for 17 children or 25% of the sample. (These percentages exceed 100% if added together because we are counting children in more than one area if the respondent listed more than one type of disability.)

There were also a few children with special medical conditions, including three children who had seizure disorders.

Lack of child care as barrier to employment

The largest number of respondents to the Study--26, or 39% of the sample, lived in households with two parents, both employed outside the home. Another 16, or 24% of the total responses, came from single employed parents. Thus 63% of the children covered in our survey were living in homes in which any available parent was contributing to the household income. Many of these parents--and a few of the others, in households where a married mother was staying home--were finding the lack of child care to be a major obstacle.

Survey respondents were asked, "Has lack of appropriate child care since your child reached age 5 ever been a barrier to your economic advancement or career development?" The majority of parents answered in the affirmative. Out of the total group of 66 parents, 35, or 53%, answered yes; while 28, or 42%, answered no. Moreover, of 20 single mothers, 15, or 75%, said that lack of child care had been a barrier to economic advancement.

Two of the single respondents had given their children up for out-of-home placement, as a result of lack of child care and respite care. Of the five single mothers who had not felt their employment options reduced by lack of child care, four were fortunate to live in either the Madison, Wisconsin, or Cleveland, Ohio, areas, where special resources were being made available to integrate children with special needs into local school-age child care programs. The fifth was apparently receiving adequate child support from a former spouse and not interested in working outside the home.

Some do not work at all; others feel limited in their work options

How had the lack of child care been a barrier to the economic advancement or career development of parents of disabled school-age children? A married mother from Virginia captured the flavor of many of the responses when she wrote, "I've had to assess each new job requirement or potential in light of hours away. The stress is so great that I've not pursued many avenues." A single, employed mother of a special needs adolescent explains that the lack of child care is "a constant and at times totally determining factor in terms of both work and leisure." A single father of a learning disabled teen-ager says, "life revolves around finding proper programs..."

For some, parenting a disabled child means not working at all. A woman who has charge of her profoundly retarded grandson explains that, "I have not been able to return to work because no one wants to care for him." The married mother of an autistic child says, "It is totally impossible for me to work outside my house. I need to be available even when he's in school...I would be an extremely unreliable employee."

Those who are working tell of lost opportunities. From Sparks, Nevada, comes this comment: "I have had an opportunity to take two jobs which would have been advancements. However, I could find no dependable, weekday, after-school care." From Lincoln, Massachusetts, similarly: "...am fortunate to have found flexible situation--do not pretend it uses my skills..." The mother of a mildly retarded child in Oregon City, Oregon, says she "had to go on an evening shift so my husband could watch our son, since a day care wasn't available." A single mother from Clearwater, Florida tells of having "had to refuse a promotion due to child care problems."

Most dramatic was this response from a single parent of a profoundly retarded and hyperactive 12 year old: "I could not take on full-time work unless I had adequate child care. When I taught part-time, there were times I had to leave him locked in the car, strapped in his seat, with the motor running to heat the car, while I taught a class..."

Other than this frightening example, survey respondents reported only a few instances in which they felt the arrangements they made were neglectful of the needs of their disabled children. On the other hand, the data make it clear that mothers--and occasionally fathers--were neglecting their own needs as a matter of course.

Most married women who were not currently in the work force, for example (a category comprising 23% of the survey sample), did not report that lack of child care had been a barrier for them. However, the proportion who believed it had been a barrier was greater among parents of those eight and older than among the parents of younger disabled children. It appeared that other factors, such as the presence of additional young children, created reasons not to be in the work force for some years. But these other reasons seemed to fall away over the years, leaving the lack of child care for the disabled child as a more significant factor.

A rather poignant survey response came from the married mother of a mildly retarded child in northern California. She did not answer either yes or no to the question about economic advancement and career development, because she did not feel that it had been a problem up to the present. But her daughter was now approaching age ten, and she was clearly rethinking her own direction: "If I thought she would be really well-provided for in a day care environment I would allow myself more time for other pursuits...Mom's career is motherhood, but after 27 years of same I would more intensely pursue my interests if possible!"

Denial of access to child care

One might wonder what kinds of efforts to obtain child care have been made by parents who report problems resulting from lack of child care for their disabled school-age children. The Study asked this question: "Since age 5, has your child ever been refused admission to a child care program or have you ever been discouraged from applying for enrollment in such a program on account of the child's disability or handicapping condition?"

Among the parents of 5 to 7 year olds, 25% answered yes to this question. Among the parents of 8 to 11 year olds, 42% answered yes. Among parents of 12 to 16 year olds, 48% answered yes.

This rising frequency of yes responses as children got older is clearly understandable. First, the parents of adolescents have had more opportunities to apply for child care; therefore, more opportunities to have been refused at least once. Second, there has been a greater awareness among child care providers about the need to accept children with special needs in the last few years than in earlier years.

Of course, even 25% is a huge percentage, considering that many parents of moderately to severely disabled children do not even apply for child care. In fact, the percentages at all age levels may be deceptively low for that very reason. A mother of a 7 year old who marked no to this question wrote this underneath: "Note: I have not tried child care programs since age 5 because I was told several places *before* he was 5 that they were not 'equipped' for his care." She is single and works "only part-time because child care has been so hard to find and keep." The mother of a 9 year old who answered no to the question explained nevertheless that she has been required by her daughter's day care center to reduce the number of hours her daughter attends, and also to pay for a teen-aged aide. ("It has been a quiet fight all the way," she wrote.)

Typically, those who said their children had been refused admission to child care programs told of providers who didn't give specific reasons for not accepting a disabled child. One parent, on the line of the questionnaire asking to "briefly describe the circumstances" relating to the denial of admission, wrote simply, "the day care was not keen on the idea of a special needs child." "I approached Latchkey," a Florida parent wrote, "about taking care of children like S--, and they felt that the needs were too great for them to meet." An Ohio mother wrote of a place she applied that just "did not accept special children." A Seattle mother found that "daycares just did not want a handicapped child with anything more serious than eyeglasses."

Sometimes there were more specific reasons given to parents for their children not being considered appropriate for enrollment. Several parents mentioned their children's behavior as a factor. In at least one instance, the parent was told that the outdoors and sports-oriented curriculum would not match the child's needs and interests.

Respondents who answered yes to this question not only told of being steered away from programs to which they applied, but also of having their children terminated from programs which they previously attended. "They felt he needed more attention than they could give him; also his behavior was disruptive," was the explanation given by a Spokane parent of a 6 year old with mental delays and behavior problems who lost her child care and has been "desperate for after-school child care" in the ensuing year. The family day care providers she has tried have been "unable to control my son's behavior and also...unwilling to learn techniques that would help with this." An Ohio parent was apparently a victim of a sudden policy change at her child's after-school center. Several mentally retarded children were put out of the program they were attending; the parents were told "they did not have the equipment or personnel for these children."

Current use of child care

How many parents of school-age children with special needs currently make use of child care? When they do, what kind of child care do they use? Under whose auspices is it run? Are they mixed in with non-disabled children in what are referred to as mainstreamed or integrated settings, or are they enrolled in specialized, segregated settings designed only for children with disabilities? If parents had a choice between the integrated variety and the segregated variety for their disabled school-age children, which would they choose? We asked the respondents to our surveys all these questions.

Out of our survey group, 27 children, or 40% of the sample, had been enrolled in some type of child care program after school (at least 8 hours per week) or during the summer within the past 12 months. This is probably a much higher number than would be found in a random population of families with special needs children, since between one-fourth and one-third of our sample learned about the School-Age/Special Needs Study from staff and administrators associated with child care programs--programs, frequently, in which their children were enrolled. (For instance, a Harvard Public Health study (*) found only 18% of disabled school-age children in a 3-city sample using after-school programs, whereas 21 children--31% of our survey sample--were enrolled in before- and/or after-school programs.)

Of this group of 27, about one-fourth had attended more than one kind of child care program during the previous year; for the remainder, parents listed only one program. The most frequent types of programs mentioned by parents were community-based after-school programs run either by local non-profit agencies or by local affiliates of national organizations such as YMCA's or ARC's (Association for Retarded Citizens). There were 12 children who had attended such programs during the past year. They ran two to four hours a day; some offered before-school programs as well. Those that were designed explicitly for the special needs population sometimes offered weekend activities as well.

Programs administered by public school districts and run either after school or before and after school were mentioned by 5 respondents. Programs run by private schools were mentioned by 4 respondents, and programs run by town recreation departments by 4 as well. One parent mentioned a program run by a county, and the administrative framework of some other programs listed was not clear.

The type of organizational affiliation of a particular program did not generally determine whether it was a mainstreamed or segregated program. Other than programs run by ARC chapters, there were examples of both segregated and integrated programs within each administrative model cited by our survey audience. Public school, private schools, recreation departments, community centers, YMCA's and nonprofit organizations were all apparently offering in various places both types of programming.

Of the children from 5 to 11 years old who had been in child care programs during the previous year, approximately half of their experience had been in mainstreamed settings. A larger proportion of those age 12 to 16 had been in some kind of program, and the majority of those programs had taken place in segregated settings.

Some children were gaining experience in both types of settings--for instance, a mentally retarded 16 year old who attended a summer day camp that was segregated and also a daily before-school program which was mainstreamed.

We did not ask parents to evaluate the quality of the child care their children were receiving. But many of them offered unsolicited comments in the section of the survey asking them to offer additional comments on any aspect of the issue. Nearly all who said anything at all about quality had praise for the child care programs which enrolled their children. But a few clearly felt that while the arrangements they had made satisfied their own needs for employment, they did not really address the child's needs for appropriate recreation and social interaction.

Mainstreamed or segregated child care: which would parents prefer?

"Life is mainstreamed--I don't believe we need to teach anyone about segregation," wrote one respondent to the School-Age/Special Needs Study, mother of a 10 year old with mental retardation, visual impairment, and a seizure disorder. But the mother of two Down Syndrome adolescents wrote with equal conviction in support of segregated after-school programs: "When adults relax and play they usually choose peers of similar abilities and interests. I want the same for my children."

"Given a choice of high quality child care environments in which you could enroll your child," the survey asked, "which of the following would you currently select for your child...Segregated environment with children with similar special needs? Mainstreamed environment?"

Out of the entire group of 66 respondents, there were 40, or 61%, who designated the mainstreamed environment as their preference, while 26, or 39%, preferred the segregated environment. More specifically, the parents of adolescents were about evenly divided on this issue, while nearly two-thirds of the respondents whose children were 5 to 11 years old liked the mainstreaming approach better.

This difference in preference between parents of younger school-agers and adolescents may reflect the reality that some noted in the survey--that when children get beyond age 11 or 12, it is very difficult to find appropriate integrated settings, since their non-disabled peers may not be attending child care or other supervised recreational programs. "I want them in age-appropriate settings," wrote the mother of the two boys with Down Syndrome, "which precludes most after-school programs which generally only serve youth up to age 10-11."

The question of whether a child was segregated or mainstreamed during the school day did not necessarily influence a parent's thinking about what would be the best child care environment. Some parents mentioned that the children were doing very well in a specialized school setting and needed the same kind of protected environment after school. The grandmother of an autistic seven year old, for instance, says "he is in a special education class and needs to be with children with similar problems." But others felt just the opposite, like this Oregon parent of a 7 year old with severe retardation and cerebral palsy: "Because he's in a segregated environment in his classroom, I feel that he needs to be in a mainstreamed environment at least part of the time in order for him to see the possibilities of life."

Special children more supported, protected in segregated setting?

Most parents who preferred the segregated environment did so because they wanted their children to feel the supportive presence of other children with special needs. Some parents of hearing-impaired children, for instance, wanted them to be with others who used the same form of communication. "I believe he would communicate his needs more easily in a group of similarly hearing-impaired children, and he in turn would understand their needs more readily," was the way the mother of a nine year old with "profound hearing loss in both ears" expressed it. The mother of a five year old with cerebral palsy put it in more subjective terms, writing that "these kids are full of lots of love for one another and it helps them learn to care for each other."

Smaller numbers mentioned that they favored segregated programs because they would expect such programs to have better trained staff, that the activities would be more appropriate to their children's needs, and that their children were not capable of interacting with non-disabled children. "Regular programs do not have qualified personnel to handle special needs," wrote, emphatically, the Florida respondent whose daughter had been turned away by a large school-age child care agency. "My daughter is not able to interact with normal children and would not make any gains with a mainstreamed environment," stated a Massachusetts parent.

There was also considerable fear expressed by those favoring segregated settings that children with special needs would not get as much attention in the integrated settings, or would get undesirable--stigmatizing--attention. "The squeaky wheel always gets the most attention," wrote one grandparent. "I feel those that are like J-- would be left out." Another respondent similarly felt that a "special child would get left out, pushed aside, or ignored in an environment with children without special needs." "I don't have to worry about teasing and name calling from the other kids," reported another survey respondent.

Several who checked a preference for segregated programs showed an ambivalence in their comments. "I would prefer some mainstreaming, but do not think A-- could handle a regular high school age group on a regular basis," said one. "Public awareness and acceptance is not as good as it could be...although it seems to be improving," commented another. Still others were hoping their children could participate in mainstreamed recreational settings within a few years, but didn't believe they were adequately prepared for it yet. "I feel at some point, not far in the future," wrote one mother of a mentally retarded and hyperactive child, "J-- with the help of all programs which he is currently involved, will prepare him for this transition."

Mainstreamed environment viewed as chance to be normal, improve skills

Parents who preferred mainstreamed environments usually gave one of two reasons: either that they wanted their children to have opportunities to "feel normal" through interaction with non-disabled children--including, in some cases, their own siblings; or they thought the mainstreamed environment would help their children to improve their social skills and be challenged intellectually and in other ways. In addition, several parents wanted non-disabled children to have a chance to become familiar with disabilities.

"I feel he needs as much contact as possible with his 'normal' peer age group and others and they can learn from him also," wrote the mother of a child with cerebral palsy who was not currently in any child care program. "Needs very much to behave and be accepted," went another typical comment, this one from the parent of a non-verbal 10 year old who participates in a mainstreamed after school center. "Others need to know how to act around him," she concluded,"it works both ways." Similarly, from the parent of an 8 year old whose point of view is different from that of some other parents of hearing-impaired children: "He attends a school for the deaf all day but when he comes home his brother and neighborhood friends are hearing and he does well adjusting to both settings."

As among the parents favoring segregated programming, ambivalence was not uncommon. One mother whose daughter has speech and hearing problems as well as physical developmental delays and who is currently enrolled in a mainstreamed program after school wrote that she prefers the mainstreamed environment, "but it is hard on my child as she is the only one that is 'different.'" Another parent whose child was not attending any program wrote that she would like the mainstreamed environment to "give her the feeling of being like other children...but staff must be trained on handling the special needs child."

Can quality safeguards be preserved in mainstreamed child care environments?

Our survey respondents wanted child care for their disabled school-age children, and they wanted it to be of high quality. In the eyes of most parents, quality superseded the question of segregation or integration. Many who said yes to segregated settings made it clear that they had a mistrust of mainstreamed environments. They did not appear to reject mainstreaming in the abstract. But they feared that in actual day-to-day practice the special needs of their children would go unaddressed in a mainstreamed environment.

Many of the respondents had children who would need very close supervision (even one-on-one in some cases). Some had medical conditions, such as seizures, or emotional disorders, such as autism, which would not be appropriately handled unless staff were to be properly trained in advance. Many also felt the presence of at least a few other children with comparable disabilities would be needed for their children not to be too isolated or stigmatized. In addition, a curriculum which took into account their interests and capabilities and an atmosphere conducive to their constructive interaction with other children would be a part of what these parents thought of as a quality environment.

If these kinds of safeguards could be built into school-age child care environments, then it appears that nearly all parents of 5 to 11 year olds would select mainstreamed child care for their disabled children. Parents of adolescents would still, it appears, be more divided, and would still face the reality that the non-disabled peers of their children are not generally enrolled in such programs.

Conclusion

The response of a single mother of a retarded son with "autistic traits," captures rather well the longing that parents have for the best possible environment for their children with special needs--and the fear that it just doesn't exist. After selecting "segregated environment" as her preference for her five year old, she adds by way of explanation, "This is a difficult question to answer because I would like to have my son exposed to 'normal' children more regularly, but with his handicaps he needs as much one on one as possible, and I assume this is not possible in a mainstreamed environment." Presently, she reports, he attends a "pretty good" segregated program which is open only two afternoons a week. She adds further that as a single mother she has been "unable to hold a job" due to the lack of child care programs.

Fortunately, some of our other respondents reported more success at finding what they really wanted for their children--though not necessarily without a great deal of heartache along the way. A single mother said her son had been "kicked out of two programs" before age five. But she was able to report to the Study that although her son is non-verbal and vision-impaired and exhibits a great deal of challenging behavior, he is succeeding at age nine in a mainstreamed after-school setting run by the YMCA in a public school. "A week after we started in this program, the teachers and director told me that possibly they could not take N-- after all because they just didn't have enough help and couldn't justify hiring another person...but as it turned out, we all hung in there, and N-- learned his limits, and teachers learned to communicate with him. Several special education kids are now enrolled."

There is a span of 6000 miles between Hilo, Hawaii, the community where that YMCA program operates in a public school cafeteria, and another island--Long Island, New York--where the previously quoted respondent agonizes over the apparent lack of options for the care of her retarded/autistic son and assumes that what she really wants is "not possible." It is clear that from one end of our nation to the other, families with disabled school-age children are thinking deeply about the question of child care. Some few seem to be obtaining the child care support they need to the extent that they are able to balance work and family life much as do parents of nondisabled school-age children. Others, meanwhile, are struggling without such support, and often making severe compromises in what they want for themselves in either work life or family life. Many give up career opportunities; a smaller number give up their children.

As one Oregon parent of a seven year old wrote in the space on the questionnaire asking for any additional comments not yet covered by the survey: "Child care is *the* problem in our life second only to my son's disability."

* Klein Walker, Deborah; Palfrey, Judith S.; Butler, John A.; Singer, Judith; and Wenger, Marta. Cited with permission of authors from draft version, paper titled "Health and Community Services for Children with Mobility Impairments: Who Provides What?" to be published by Public Health Reports.